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ABSTRACT

In recent years, sickle cell screening programs have been initiated by community groups, health centers, hospitals, medical schools, health departments, school systems, city and State governments, various branches of the Federal Government, fraternal and social clubs, and other organizations. Problems have resulted from mass sickle cell screening, and to date, the results of the concerted efforts of many groups have been more harmful than beneficial. City and State governments have passed questionable mandatory sickle cell laws. This paper includes a discussion of the legislation passed by three such states; Massachusetts, Virginia, and the District of Columbia. These states have passed mandatory sickle cell screening laws involving one or all of the following groups: preschool and school children; potential marriage partners; and inmates of correctional and mental institutions. It is urged that these mandatory sickle cell screening laws be repealed. If sickle cell screening programs are to be made available, they should be available on a voluntary basis in accordance with guidelines already established by the Department of Health, Education and Welfare. Sickle cell screening programs should be organized so as to offer strong educational programs, primary sickle cell screening which will allow the ascertainment of the hemoglobin genotype and confidential expert and humane genetics counseling. The misinformation which has already been fostered by large sickle cell screening programs and pressure groups already has resulted in psychological and social damage in the black community. (Author/AM)

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SICKLE CELL SCREENING—MEDICAL-LEGAL, ETHICAL, PSYCHOLOGICAL AND SOCIAL PROBLEMS: A SICKLE CELL CRISIS

U.S. DEPARTMENT OF HEALTH, EDUCATION & WELFARE
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In recent years, sickle cell programs have been initiated by community groups, health centers, hospitals, medical schools, health departments, school systems, city and State governments, various branches of the Federal Government, fraternal and social clubs, private corporations, and many other organizations. More recently, the Federal Government has approved funds for comprehensive sickle cell centers and for screening, education, and counseling clinics.[1] These federally-supported programs will begin on July 1, 1972. The National Foundation-March of Dimes supports several sickle cell projects, and private organizations throughout the country have been chartered for the purpose of sickle cell program fund raising.

✓Problems have resulted from mass sickle cell screening, and, to date, the results of the concerted efforts of many groups have been more harmful than beneficial. City and State governments have passed ill-advised mandatory sickle cell laws[2-4] which could revive past misadventures and racism or eugenics[5] movements. Sickle cell screening is being conducted by persons unfamiliar with the basic techniques of laboratory technology and with no access to (and refusing) medical, hematological, or genetic counseling expertise. Laws have been proposed which would exempt Afro-Americans with sickle cell trait and/or glucose-6-phosphate dehydrogenase deficiency from military service or to limit duty assignments of such soldiers.[6,7] Some companies are reported to have increased life and health insurance rates for persons who have sickle cell trait (HbAS). Airlines do not now allow employees who have sickle cell trait to fly, and long-standing airline employees who are discovered to be HbAS are grounded. Inaccurate, misleading, politically motivated propaganda has left mothers frantic.

Massachusetts has recently passed a law entitled:

"BLOOD TEST FOR SICKLE CELL TRAIT OR SICKLE CELL ANEMIA:[9]

Every child, which the commissioner of public health, by rule or regulation, may determine is susceptible to the disease known as sickle cell trait or sickle cell anemia, shall be required to have a blood test to determine whether or not he has such disease before being admitted to a public school, or in the first year of attendance in a public school. Such rule or regulation shall include provisions for the preparation and distribution of educational materials relating to sickle cell trait and sickle cell anemia."

The District of Columbia City Council on May 3, 1972 adopted:[10]

"REGULATION REQUIRING IMMUNIZATION OF SCHOOL CHILDREN:

WHEREAS, the District of Columbia pursuant to paragraph 4, Section 402, Reorganization Plan No. 3 of 1967 is empowered to enact regulations concerning the health and general welfare; and

WHEREAS, pursuant to Section 6-118 D. C. Code (1967 edition) and paragraph 134, Section 402, Reorganization Plan No. 3 of 1967, the Council is empowered to issue regulations to prevent and control the spread of communicable diseases.

NOW, THEREFORE, BE IT ENACTED by the District of Columbia Council that:

Section 1. Each child admitted into the public or private schools, either kindergarten or the first grade as the case may be, shall have been immunized or otherwise protected against measles, poliomyelitis, tetanus, and diphtheria.

Section 2. Each child admitted to a public school either kindergarten or the first grade as the case may be, shall have been tested for sickle cell anemia.

Section 3. No vaccination, immunization or medical test shall be required of any child whose parent or guardian objects thereto in writing on grounds that such vaccination, immunization or medical test is contrary to his religious teachings and practices, nor shall such immunization or medical tests be required in the case where a medical doctor certifies in writing that medical contraindications are present.

Section 4. The Director of the Department of Human Resources or any successor thereto shall develop and implement such plans or policies necessary to insure that such immunization and testing required by this regulation is accomplished so as not to interfere with the normal school attendance; provided that such immunization and testing is done without fee or charge and further provided that such immunization and testing is accomplished at the earliest age is medically prudent and feasible. Further, the Director shall develop and implement a program of sickle cell anemia testing or screening for students who are already in school as well as a program to assure the immunization and testing of students in preschool programs.

Section 5. This regulation shall take effect September 1973, provided that should sufficient funds become available on an earlier date, the implementation of this regulation may be initiated at the direction of the Director of the Department of Human Resources."

And Virginia:[11]

"Be it enacted by the General Assembly of Virginia:

1. That the Code of Virginia be amended by adding in Title 32 a chapter numbered 5.2, containing sections numbered 32-112.10 through 32-112.19, as follows:

Chapter 5.2

§ 32-112.10. In order to protect and preserve the health and welfare of the citizens of the Commonwealth, every parent, guardian, or other person in the Commonwealth, having control or charge of any child who has reached his sixth birthday shall present the child to a duly licensed physician for sickle cell trait test and such physician shall perform or cause such sickle cell trait tests to be performed as he, in his professional judgment and discretion, deems necessary or required. Such tests and tests' results shall be reported to the State Health Department on reporting forms which shall be prescribed and furnished by the State Health Department.

§ 32-112.11. Every child in the Commonwealth shall, on or within thirty days after beginning attendance in a public kindergarten, elementary or secondary school in the Commonwealth, furnish a certificate from a duly licensed physician certifying that such child has been tested for sickle cell trait or that such tests are not, in his professional judgment and discretion, deemed necessary.

§ 32-112.12. The State Board of Health shall adopt regulations and procedures to establish, maintain, promote, and carry out an intensive program to educate the general public regarding the nature and inheritance of the sickle cell trait and sickle cell anemia and shall consult with and advise the State Board of Education with respect to development of informational and educational materials relating to sickle cell trait and sickle cell anemia.

§ 32-112.13. The State Board of Health shall promulgate rules and regulations it deems necessary concerning the obtaining of samples or specimens as may be required for the tests prescribed by the State Board of Health, for the handling and delivery of

the same, and for such tests as may be required to detect and diagnose the sickle cell trait.

§ 32-112.14. In addition to such pre-marital tests and examinations as may be required by Chapter 1 of Title 20 of the Code, the physician who performs or causes such tests and examinations to be performed shall, when in his professional opinion and discretion he deems it necessary or desirable to perform or cause to be performed sickle cell anemia tests or sickle cell trait tests, make known to both parties for whom the marriage license is desired the availability of such tests, the purpose of such tests, the nature of sickle cell anemia and sickle cell trait, and the possibilities of transmitting the trait to children.

§ 32-112.15. The State Department of Health shall furnish all physicians, public health nurses, hospitals, maternity hospitals, State and local welfare departments and agencies, and the general public, available medical information concerning the nature and effects of sickle cell anemia and sickle cell trait. Further, the State Department of Health shall prescribe and furnish all necessary reporting and other forms which are required by this chapter.

§ 32-112.16. Such tests as required by § 32-112.10 shall not be given or required of any child whose parent or guardian objects thereto on the grounds that such test conflicts with his religious practices or tenets.

§ 32-112.17. Sickle cell trait tests required by this chapter shall be made by the State Department of Health for any person unable to afford the services of a private physician, or by a laboratory approved for such purpose by the State Health Commissioner. No charge shall be made for any such tests made by the State Department of Health.

§ 32-112.18. The physician's certificate as required by this chapter may be executed, for any person unable to afford the services of a private physician, by any State Health Department clinic physician or any county, city or town health officer, who is also a registered physician; and when so made, no charge shall be made therefore by such clinic physician or health officer.

§ 32-112.19. The chief physician of each State correctional institution and State mental hospital shall perform or cause to be performed sickle cell anemia and sickle cell trait tests on those inmates of such institution who in his professional judgment would benefit thereby. The results of such tests shall be made a part of the permanent medical record of such inmate."

These mandatory sickle cell screening laws are unjustified, potentially discriminatory, and have the potential for considerable damage. Each law will be analyzed separately. The potential harm of such legislation will be demonstrated, and it will be established that these laws are in opposition to some ethical and social criteria which have been proposed for screening for genetic disease.

The Commonwealth of Massachusetts: The first sentence of the law is vague, ambiguous, and misleading: "... Every child, which the commissioner of public health, by rule or regulation, may determine is *susceptible to the disease* (italics mine) known as sickle cell trait or sickle cell anemia...." Hemoglobin S is found in high frequency in Africans and their descendants, Greeks, Sicilians, Arabs, Southern Iranians, Asiatic Indians, some Amerindians, and in some Mexican populations. Africans and their descendants include in the Americas: Afro-Americas, Puerto Ricans, some populations of the Caribbean, and Central and South America. In some regions of Greece, the HbAS frequency approaches 30 per cent—three times the frequency in Afro-Americans and more than twice the frequency of HbAS in northern Ghanaians. In some populations of India, the prevalence of HbAS is higher than that found in Afro-Americans. Additionally, many so-called whites in the United States have African ancestors. Thousands of Blacks "pass" permanently into the white population each year. It has been estimated that on the basis of three hundred and fifty years of matings between Blacks,

whites, and "passing" Blacks that approximately 21 per cent (1 in 5) of whites are descendants of Africans.

It would, therefore, follow that the commissioner of public health of the Commonwealth of Massachusetts can only determine who is: ". . . susceptible to the disease known as sickle cell trait or sickle cell anemia" by screening all children. Since Blacks constitute only 3 per cent of the population of the State of Massachusetts, I would doubt seriously that the State would spend funds to test all school children. Nevertheless, if *all* are not tested, then a good case can be developed to show that the Massachusetts law is class discriminatory and is thus unconstitutional. (The same argument could also be used against airline employers who test for sickling only those whom they classify as Black.) The implication in the law that sickle cell trait should be termed sickle disease is contrary to the opinion of many hemoglobin experts. Sickle cell disease is best defined as a disease that results from HbS in the *homozygous* form or of HbS in combination with another abnormal hemoglobin.[12] The language of the Massachusetts law (sickle cell trait = disease) could lead to considerable psychological trauma.

The second part of the sentence ". . . shall be required to have a blood test to determine whether or not he has such disease before being admitted to a public school, or in the first year of attendance in the public school" violates accepted proscriptions against mandatory genetic screening. Genetic screening programs should be conducted on a voluntary basis. There is currently no public health justification for mandatory screening for prevention of genetic disease, and the rationale for genetic screening of preschool minors or preadolescents is questionable. Genetic screening should also properly be considered a form of "human experimentation." There is a risk of possible psychological or social injury.[13] It has been proposed that screening programs should be conducted according to the guidelines set forth by the Department of Health, Education, and Welfare for the protection of research subjects.[14] Let us now analyze the District of Columbia law.

The District of Columbia law is particularly objectionable.[15] The legal maneuver to declare an hereditary disease communicable reduces law to an absurdity, one could set A=B and create any legislation. Such a precedent, could also lead to regulations about blue eyes, Jews, Catholics, etc. The next step could be to legislate mandatory amniocentesis or placentesis laws for mothers whose fetuses are at risk for sickle cell disease. The District of Columbia legal counsel publically acknowledged that parents who do not wish their children tested could either go to jail or send their children to a private school.[16] Thus, this is still another law which is selective for the poor. Since I became aware of the District of Columbia Sickle Cell Communicable Disease law, I learned from several lawyers that it is indeed a common legal maneuver to set A=B where a legal manipulation is desired. There is also the famous decision of Justice Oliver Wendell Holmes in *Buck vs. Bell*.[16] (This distinguished jurist was also a staunch eugenicist, as were many leading Americans of his day.) This landmark decision of the U.S. Supreme Court may be offered as a precedent for mandatory sickle cell screening laws, with the exception that the mental defective state was not declared a communicable disease. The *Buck vs. Bell* case was that of a feebleminded Carrie Buck. Carrie Buck was born of a feebleminded mother and was adopted at the age of four by a family in Charlottesville, Virginia. She attended school until the sixth grade, became recalcitrant and then pregnant. Her child was born in an institution for epileptics and the feebleminded. Carrie's mother had a mental age of seven years and eight months; Carrie's mental age was nine; her six-month-old baby was supposed to be mentally defective. Sterilization was ordered and upheld by the Circuit Court. In the spring of 1927, the U.S. Supreme Court in the famous Holmes decision, *Buck vs. Bell*, held that sterilization fell within the police power of the state. Justice Holmes wrote: ". . . We have seen more than once that the public welfare may call upon the best citizens for their lives . . . It would be strange if it would not call upon these who already sap the strength of the State for these lesser sacrifices, often not felt to be such by those concerned, in order to prevent our being swamped with incompetence. It is better for all the world, if instead of waiting for their

imbecility, society can prevent those who are manifestly unfit from continuing their kind. The principle that contains compulsory vaccination is broad enough to cover cutting the Fallopian tubes.... (and in a famous aphorism he concluded)... Three generations of imbeciles are enough." There was only one dissent. The Supreme Court thus put its seal of approval upon the Virginia sterilization law. This now brings us to the Commonwealth of Virginia and its sickle cell law.

The Virginia sickle cell law does not go as far as the District of Columbia in declaring sickle cell trait and sickle cell disease communicable, but it does have some features which are not present in either the Massachusetts or in the District of Columbia law. Firstly, the legislation is carelessly written. The physician is to make known the availability of sickle cell tests, the purpose of such tests, the nature of sickle cell anemia, and sickle cell trait and the *possibilities of transmitting the trait* to children (§ 32-113.14). Of course, the transmission of sickle trait is not the problem; the probability of an HbSS or an HbS/abnormal hemoglobin child in offspring of parents each of whom has an abnormal hemoglobin *allele* is important.

Secondly, in view of the past history of the State of Virginia (this state is one of 23 states which have *compulsory sterilization laws for mental defectives* (§ 32-112.19)[17,18]) I am concerned about the ominous feature of the sickle cell law which includes inmates of correctional institutions and State *mental* hospitals. There is no valid reason why inmates of correctional institutions and mental hospitals should all be tested, and the potential for mischief is too great for this section of the law to be disregarded. Scientific knowledge has in the past been perverted to fulfill social ends, and there is, unfortunately, nothing in the history of the State of Virginia or of the United States, for that matter, which would lead one to believe that there is no basis for alarm. There are no compulsory or voluntary sterilization laws in Great Britain, France, or Italy. Germany had compulsory sterilization laws during the Nazi period; however, the Allies in 1946 abolished these laws, and they have not been re-enacted. These laws were used by the Nazis in their genocide program. On the other hand, the Americans who abolished these laws did not work to abolish similar laws at home.[17,18] Even so, since the initial case in the Supreme Court upholding compulsory sterilization, two other cases have come before the Court. In each, the Court declared the compulsory sterilization statute unconstitutional on the technical ground of denial of equal protection of the laws.[19] Thus, there is hope. Compulsory sterilization laws should not exist; neither should legislation which directs compulsory sickle cell screening. Of course, it could be argued that legislators of the District of Columbia and the States of Virginia and Massachusetts acted only out of solicitude over the plight of Blacks. On the other hand, the conditions which lead to high maternal and infant mortality rates in ghettoes: malnutrition, deaths from fire-trap housing, educational demise in public schools, and massive unemployment are correctable with present knowledge and must have higher priority than sickle cell screening. The District of Columbia, the State of Virginia, and the State of Massachusetts have not altered priorities and conquered these preventable social illnesses.

According to Senator Kennedy:[20] "... We know very well the dismal health record of the United States compared to the other major industrial nations of the world. Our rates of sickness and mortality lag far behind the potential of modern health care in America, or the reality of such care in many foreign nations. Year after year, the statistics tell us how little progress we have been making in health care in recent decades compared to other nations. Our record is getting no better. Unless we stop the slide, the crisis will get worse, and the result will be disaster. The comparisons are shocking: In infant mortality, among the major industrial nations of the world, the United States trails behind 12 other countries, including all the Scandinavian nations, most of the British Commonwealth, Japan and East Germany.... We trail six other nations in the percentage of mothers who die in childbirth.... Tragically, the infant mortality rate for nonwhites in the United States is nearly twice the rate for whites. And nearly five times as many nonwhite mothers die in childbirth as whites—shameful evidence of the ineffective prenatal and postnatal care our minority groups receive."

In the age group 0-1 year, based on 1968 data,[21] the national death rate per 1,000 for white males was 21.8 and for white females 16.3; the death rate for nonwhite males was 37.7 and nonwhite females, 31.1. In the States of Massachusetts and Virginia and the District of Columbia in 1968,[22] the infant mortality rates per 1,000 births were as follows:

	White	Nonwhite
Massachusetts	19.2	34.6
Virginia	19.0	33.2
District of Columbia	20.9	30.3

Let us now leave these sickle cell laws and deal with some other medical-legal aspects of sickle cell screening. Screening for genetic abnormalities requires an understanding of educational techniques, and community problems, expertise in laboratory techniques, and genetics counseling. The misinformation which results from inaccurate education, inexpert testing, and injudicious genetics counseling can lead to irreparable damage to the propositus, the family, and the community.

Some sickle cell public education bulletins, for example, classify sickle cell trait as a form of sickle cell disease, like the Massachusetts law. I will quote from a popular educational brochure, but I will not name the organization. "What is Sickle Cell Disease? Sickle Cell Disease is a serious blood disorder that can be painful and sometimes fatal. It is a genetic disease. It affects both sexes equally. It occurs in both mild and a severe form. Many victims of the severe form die before the age of 40. At present it is incurable." The Heart and Lung Institute, National Institutes of Health in a news release reported:[23] "...BACKGROUND INFORMATION—SICKLE CELL DISEASE. Sickle cell disease, the most common inherited disorder in the U.S., is believed to be present in more than 2 million Black U.S. Citizens. Although the disease occurs in a relatively benign "carrier" form in most of these 2 million." Sickle cell disease also is *not* the most common inherited disorder in the United States. Glucose-6-phosphate dehydrogenase (G6PD) deficiency is found in many more populations in the United States than is HbS. Additionally, G6PD deficiency, an X-linked disorder, is found in about 10 per cent of Afro-American males[24] and in 18 per cent of Black females.[25] This information was reportedly released by the Sickle Cell Disease Advisory Committee apointed by the Secretary of the Department of Health, Education, and Welfare, but the members of this distinguished committee must not have seen the final draft of the news release.

The designation of sickle cell trait as a disease has led to an understandable anxiety among mothers who are inundated by misleading literature from community and other organization. It is likely that many of the harmful effects[26] of sickle cell trait have been greatly exaggerated.[27,28] There is no doubt that HbS/thalassemia has been misdiagnosed as sickle cell trait (HbAS). Konotey-Ahulu[27] and Addae[29] warn against this common error. Konotey-Ahulu also maintains[28] and quotes Lehmann to the effect that the harmful effects of high altitude on subjects with sickle cell trait have been overestimated. If Black athletes who have HbAS can compete successfully at 7,500 feet at Mexico City, the potential high altitude danger to persons with HbAS could very well be the exception rather than the rule. At any rate, it has been established that there is no difference in life expectancy in the United States between Afro-Americans with HbAS and those with HbAA.[30] Thus, there would appear to be no current medical reason why persons with HbAS should pay higher insurance premiums than persons with HbAA. Sickle cell screening is best performed by *primary* hemoglobin electrophoresis[31] and *subsequent testing* of all abnormal hemoglobins for sickling by one of several sickling or solubility tests.[32]

Since this workshop deals with medico-legal problems, I will confine my comments to the possible legal consequences of misleading genetic screening. If sickle cell ascertainment is performed initially by solubility tests, as many screening centers are now doing, persons with

HbAC, HbCC, and HbA/thalassemia and subjects with many other nonsickling hemoglobins in single or in double dose are being missed. If such persons who have abnormal hemoglobins are told that they have normal hemoglobin and if they then marry partners with HbAS, they could have children who are HbSC, S/thal, or S/any abnormal hemoglobin. The investigators who are responsible for inadequate screening techniques could very well be held *liable* for damages. Injudicious genetic counseling can lead to considerable harm to a family. Often, it is impossible to arrive at a complete diagnosis of the hemoglobin alleles in a patient unless the family is thoroughly studied. In fact, family studies should be part of any screening program. It has been reported that the illegitimacy rate among Blacks is close to 45 per cent of births.[33] If these statistics are anywhere near reliable, then many exceptions to the laws of heredity will be found. For some odd reason, very elaborate plans (and laws) are formulated for counseling of prospective marriage partners, and these very important birth statistics are ignored. Surely, such programs are quite naive under present conditions. Elaborate genetic screening projects must recognize the real world. I am also deeply troubled over the prospect of making the results of mandatory screening (or any screening) a part of state records. This is an unacceptable intrusion on privacy. Often I am asked, "What do you do if tests show a child is *HbAS* and *neither* parent has *HbS*?" My answer is simply, "I do not inform the parents, and, if necessary, I go as far as to say that the test tubes containing the blood of the parents were broken in the centrifuge." This I consider the humane side of genetics counseling. Expert genetic counselors do not destroy families. Broken and incomplete families are already a major problem in Black communities without the intrusion of inept; indifferent counselors.

Within the past several months, it was reported in the *Washington Post* that at least thirty-seven Congressmen were in favor of legislation to defer persons with HbAS from military service. Recently, I asked Colonel Marcel E. Conrad, Director, Division of Hematology, Walter Reed Army Institute of Research, Walter Reed Army Medical Center, Washington, D.C., if he knew of any law suits which might be pending against the Army with respect to persons with HbAS. There is at least one. A *Common Cause Suit* instituted by the Legal Aid Society of the State of California in San Francisco has asked that a client who has sickle cell trait be declared unfit for military duty. Now, Legal Aid Societies have a reputation for enlightened action in communities all over the United States. Nevertheless, in this particular situation, with friends such as the Legal Aid Society Blacks need no enemies. If the Legal Aid Society is successful in this suit, the harm which will ensue may be irreparable. The Armed Forces of the United States has approximately 2,861,000 personnel, with Afro-Americans accounting for about 279,000 or 9.8 per cent.[34] Thus, approximately 28,000 Blacks in the Armed Forces would be expected to have sickle cell trait. If the Legal Aid Society is successful, these Blacks would have to be discharged from the Armed Forces—large numbers are career men with many years of service. There would, of course, be no *service connected disability* as partial compensation for HbAS is hereditary.[7] Of course, if the Legal Aid Society were to win this suit, then the next action would be to declare persons with glucose-6-phosphate dehydrogenase deficiency ineligible. Now, approximately 20 per cent of Afro-Americans (56,000) would be discharged from the Army. (Since females are not included in this estimate, the figure would be higher.) The Armed Forces of the United States is a major employer of Afro-Americans. It is highly likely that with the advent of a Volunteer Army, with greatly increased benefits, the percentage of Blacks who may wish to enlist or re-enlist will increase. With this prospect in mind, I see no reason why all of the white supremicist organizations in the United States would not happily join with the Legal Aid Society in an *amicus curiae* (friend of the court) brief. Once persons who have HbAS are declared unfit for military service, this would be a permanent part of their health record. Insurance rates could then rise. Any job which requires physical effort such as sports, construction work, police force, fireman, mailman, and others could be barred to persons (approximately 4,000,000 Afro-Americans) who are so deferred. Discrimination is already rampant in our society. The Black community can not afford to be further penalized as a result of sickle cell trait propaganda.

Now, if during the current period of increasing conservatism in the United States, the courts wish to attempt a definition of Afro-American, then many intriguing arguments are possible. Although races (if one wishes to use the term), populations, or ethnic groups are collectively

fairly scientifically defined by human population geneticists, *individual* racial identification is fraught with precedence and social prejudice that has little or no scientific basis. (We grant, of course, that even a four year old child can distinguish between Africans and Swedes.) Nevertheless, there are some peculiar racial equations.

Generally, in the United States, individuals with one white ancestor and the others Black is Black, and with one Black ancestor and the others white also Black. (Is this another example of Black Power?) Persons who are classified as Black in the United States may be categorized white in Brazil. Puerto Ricans who have a high prevalence of HbAS may be classified as white in some communities in the United States and Black in others. Thus, the question of who is to be tested could defy rational planning of compulsory *selective* sickle cell programs. Thus, even if the laws are not repealed, implementation of selective sickle cell screening of Blacks could be difficult to impossible. For those who still insist on class action against Blacks who have sickle cell trait, I reply that persons with red hair or blonds do have an increased susceptibility to carcinoma of the skin as a result of exposure to the ultraviolet rays of the sun. About *10 per cent* of white males in the southern United States develop cancer of the skin during their lives, but cancer of the skin is quite rare in Afro-Americans.[38] Do redheads or blonds pay higher insurance rates than non-redheads? Should the Armed Forces bar redheads or blonds from duty in the southern United States or in desert regions, or in tropical countries? (Carcinoma of the skin would be a service connected disability.) I have no doubt that the answer to these questions is, No. A small percentage of females who are heterozygous for hemophilia A have mild bleeding signs.[36] Do women who are heterozygous for hemophilia A pay higher insurance rates than women who do not have the hemophilia A allele? The answer is, No. Carcinoma of the penis is uncommon in circumcised males and is usually found only in uncircumcised males.[35] Do uncircumcised males pay higher insurance rates than circumcised males? Once more the answer is, No. Although the evidence is not as strong, the prevalence of carcinoma of the cervix may be higher in women who are married to uncircumcised males than in women who are married to circumcised males. To my knowledge, there are no differential insurance rates between these groups.

Persons who are Rh negative (whites 15 per cent; Blacks 6 per cent) are clearly at a higher risk for illness than are adults who are Rh positive. Rh negative women frequently have anti-Rh_o(D) antibodies in their plasma. If they require emergency blood transfusion, there is an increased likelihood of a hemolytic reaction as compared to persons who do not have antibodies. And there is more of a likelihood that Rh negative men will be sensitized to blood transfusion than Rh positive men. (Blood transfusions are common in the Armed Forces.) Do Rh negative persons pay higher insurance rates than Rh positive persons, or are they unfit for military duty? No. The more genetic loci are examined, the more it becomes evident that variability is the rule not the exception.[37] Some genetic variations are disadvantageous in one environment and advantageous in another. Most variations, however, are without obvious harmful effect. Recently, it has been reported (but not yet confirmed) that persons who have glucose-6-phosphate dehydrogenase (G6PD) deficiency may be more resistant to cancer than those who are non-G6PD deficient.[38] Thus, the potential harmful effects of G6PD deficiency may be balanced by increased resistance to cancer. And, for the benefit of eugenicists, Afro-Americans have overcome the perils of the most oppressive slavery in the history of man and hundreds of years of the most base human degradation, continuing to the present. This most certainly belies the past and current assertions of the eugenicists, who were the philosophical offspring of Darwinian evolution, that the survivors of slavery are "unfit." Flying in pressurized aircraft is a picnic compared to what the black ancestors of grounded airline employees had to endure and overcome. It is suggested that considerable caution must be exercised in penalizing persons who are different, for *we are all different.*

CONCLUSIONS

Massachusetts, Virginia, and the District of Columbia have passed mandatory sickle cell screening laws involving one or all of the following groups: preschool and school children,

potential marriage partners, and inmates of correctional and mental institutions. It is urged that these mandatory sickle cell screening laws be repealed. If sickle cell screening programs are to be made available, they should be done so on a voluntary basis in accordance with guidelines already established by the Department of Health, Education, and Welfare. As a corollary, it would follow that Federal support should not be used to support mandatory sickle cell screening programs.

Sickle cell screening programs should be organized so as to offer strong educational programs, primary sickle cell screening which will allow ascertainment of the hemoglobin *genotype* and *confidential* expert and humane genetics counseling. Unfortunately, the misinformation which has already been fostered by large sickle cell screening programs and pressure groups already has resulted in incalculable psychological and social damage in the Black community. There is no current medical or other justification for the deferment of persons with sickle trait from the Armed Forces. The social consequences of such an act would do irreparable damage to the Black community.

Along the same lines there is no rationale for compromising the life or health insurability of persons with sickle cell trait. There is also no justification for the grounding of airline employees with sickle cell trait who fly in pressurized aircraft or in restricting the physical activity of such persons.

REFERENCES

1. Program Announcement and Workscope. Comprehensive Centers of Research and Service in Sickle Cell Disease, Sickle Cell Disease Program, Department of Health, Education, and Welfare, November 1, 1971.
2. Commonwealth of Massachusetts, Chapter 491 of Acts and Resolves, 1971 §15A.
3. District of Columbia City Council. Regulation Number 72-9, May 3, 1972.
4. Commonwealth of Virginia. An Act to Amend the Code of Virginia by Adding in Title 32 a Chapter Numbered 32-112.10 through 32-112.19, Relating Generally to the Detection and Control of Sickle Cell Trait, April 10, 1972.
5. Haller, M. H. *Eugenics. Hereditarian Attitudes in American Thought.* Rutgers University Press: New Brunswick, N. Y. 1963.
6. Riccardi, V. M. and Hecht, F. Military Ethics and G-6-PD Deficiency. *New Eng. J. Med.* 286:947-948, 1972.
7. Conrad, M. E. (Personal Communcation)
8. Webb, E. B. Legal Considerations – Screening and Treatment – Sickle Cell Anemia. Symposium, Sickle Cell Anemia, National Foundation – March of Dimes: Washington, D.C., May 12-13, 1972.
9. Livingstone, F. B. *Abnormal Hemoglobins in Human Populations,* Aldine: Chicago, 1967.
10. Deliyannis, G. A. and Tavlarakis, N. Compatibility of Sickling with Malaria. *Brit. Med. J.* 2:301-303, 1955.
11. Lincoln, C. E. Color and Group Identity in the United States (quotes Professor R. Stuckert of Ohio State University) *in Color and Race*, Edit. Franklin, J. H.; Beacon Press: Boston, 1968.
12. Konotey-Ahulu, F. I. D., Computer Assisted Analysis of Data on 1,697 Patients Attending the Sickle Cell/Haemoglobinopathy Clinic of Korle Bu Teaching Hospital, Accra, Ghana. Clinical Features: I. Sex, Genotype, Age, Rheumatism and Dactylitis Frequencies. *Ghana. Med. J.* 10:241-260, 1971.
13. Lappe, M., Gustafson, J. M. and Robin, R., Ethical and Social Issues in Screening for Genetic Disease. A Report from the Research Group on Ethical, Social and Legal Issues in Genetic Counseling and Genetic Engineering of the Institute of Society, Ethics and the Life Sciences. *New Eng. J. Med.* 286:1129-1132, 1972.
14. The Institutional Guide to DHEW Policy on Protection of Human Subjects. Grants Administration Manual. Chapter 1-40. (DHEW Publication No. [NIH] 72-102). Washington, D. C. Division of Research Grants. Department of Health, Education and Welfare, 1971.

15. Bowman, J. E. Sickle Cell Anemia – A New Communicable Disease, *New Eng. J. Med.* (In press.)

16. Webb, E. B. (Personal communication.)

17. Meyers, D. W. The Human Body and the Law. A Medico-Legal Study, Aldine: Chicago, 1970.

18. Curran, W. J. (Book Review) *Ibid, Science,* 171:53, 1972.

19. Pilpel, H. P. The Law Social Welfare and Planning (pgs. 41-47) in *Family Planning. The Role of Social Work.* Perspectives in Social Work, Vol. II, Edit. Haselkorn, F. Adelphi U. School of Social Work Publication: N. Y., 1968.

20. Kennedy, E. M. Health Security for America, *Congressional Record,* Proceedings and Debates of the 92nd Congress, First Session, Monday, January 25, 1971.

21. Family Almanac, 1972, New York Times, New York, pg. 305.

22. *Ibid.* pgs. 173, 204, 228.

23. HEW NEWS, National Heart and Lung Institute, National Institutes of Health, November 9, 1971.

24. Carson, P. E. and Frischer, H. Glucose-6-Phosphate Dehydrogenase Deficiency and Related Disorders of the Pentose Phosphate Pathway, *Am. J. Med.* 41, 744-761, 1966.

25. Bowman, J. E. Blood Anthropology: Principles of Collection and Statistical Analysis of Data., *Int. Path.* 7:92-97, 1966.

26. Jones, S. R., Binder, R. A. and Donowho, E. M. Sudden Death in Sickle Cell Trait. *New Engl. J. Med.,* 282:323-325, 1970.

27. Konotey-Ahulu, F. I. D. Sickle Cell Trait and Altitude. *Brit. Med. J.,* 1:177-178, 1972.

28. Konotey-Ahulu, F. I. D. An International Sickle Cell Crisis. *Ghana Med. J.,* 1:4-8, 1972.

29. Addae, R. O. Sickle Cell Trait and Altitude. *Brit. Med. J.,* 1:53, 1972.

30. McCormick, W. F., Kashgarian, M. Abnormal Hemoglobins. V. Age at Death of Patients with Sickle Cell Trait. *Am. J. Hum. Gen.,* 17:101-103, 1965.

31. Barnes, M. G., Komarmy, L., Novack, A. H. A Comprehensive Screening Program for Hemoglobinopathies. *JAMA,* 219:701-705, 1972.

32. Bowman, J. E. Technical Pitfalls and Considerations in Sickle Cell Screening Programs, Symposium, Sickle Cell Anemia, National Foundation – March of Dimes: Washington, D. C., May 12-13, 1972.

33. Family Almanac, 1972, New York Times, New York, pg. 494.

34. Statistical Abstracts for 1971, U. S. Bureau of Census, Department of Commerce, Washington, D. C., Superintendant of Documents #C-3, 134:971, p. 253.

35. MacMahon, B. Cancer. *In Preventive Medicine.* Edit. Clark, D. A. and MacMahon, B. Little Brown and Co.: Boston, 1967.

36. Brinkhous, K. M. Edit. *The Hemophilias,* University of North Carolina Press: Chapel Hill, 1964.

37. Harris, H. *The Principles of Human Biochemical Genetics.* American Elsevier, Inc.: N. Y., 1970.

38. Sulis, E. G-6-PD. Deficiency and Cancer. *Lancet,* 1:1185, 1972.